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Chronic Illness in Non-heterosexual Contexts: An Online Survey of Experiences

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ABSTRACT

In this article we contribute to the expansion of lesbian, gay, bisexual, transgender and queer (LGBTQ) health psychology beyond the confines of sexual health by examining the experiences of lesbian, gay and bisexual people living with non-HIV related chronic illness. Using a (predominantly) qualitative online survey, the perspectives of 190 LGB people with 52 different chronic illnesses from eight countries were collected. The five most commonly reported physical conditions were arthritis, hypertension, diabetes, asthma and chronic fatigue syndrome. Our analysis focuses on four themes within participants' written comments: (1) ableism within LGBT communities; (2) isolation from LGBT communities and other LGB people living with chronic illness; (3) heteronormativity within sources of information and support and; (4) homophobia from healthcare professionals. We conclude by suggesting that LGBTQ psychology could usefully draw on critical health psychology principles and frameworks to explore non-heterosexual's lived experiences of chronic illness, and also that there remains a need for specifically targeted support groups and services for LGB people with chronic illnesses.

Key Words: bisexual health, chronic illness, gay men's health, heterosexism, lesbian health, LGBTQ health, online survey, patients' perspectives

INTRODUCTION

While much health research has focused on lesbians', gay men's and bisexuals' (LGB)¹ sexual and mental health, little research, to date, has examined LGB people's experiences of chronic illnesses, with the exception of HIV/AIDS amongst gay and bisexual men (e.g. Hodges and Rodohan, 2004) and breast cancer amongst lesbian and bisexual women (e.g. Matthews, 1998; Wilkinson, 2002). Unlike HIV/AIDS, other chronic illnesses are not typically considered 'lesbian or gay health issues', which the US National Gay and Lesbian Task Force defined as 'diseases or conditions which are unique, more prevalent, more serious and for which risk factors and interventions are different' for lesbians or gay men (Plumb, 1997: 365). Using this definition, lesbian health activists have framed breast cancer as a 'lesbian health issue', asserting that lesbians have a higher risk of developing breast cancer because of being less likely to have children and suggestions that, on average, lesbians may have higher alcohol consumption and weigh more than heterosexual women (Rankow, 1995).

Other chronic illnesses that have been considered in non-heterosexual contexts within the health literature include colon and rectal disease (Lipton, 1998) and prostate cancer (Perlman and Drescher, 2005) among gay men and cervical cancer among lesbians (Fish and Wilkinson, 2000; Price et al., 1996). In one of the few studies that look at lesbian and bisexual women's experience of other chronic illnesses, Sara Axtell (1999) conducted semi-structured interviews with lesbian and bisexual women (and their partners) with a range of chronic illnesses including multiple sclerosis, diabetes and fibromyalgia. Axtell documented a number of challenges in developing a disability/chronic illness identity, and while some participants felt that there were interconnections between chronic illness and their sexuality, others felt that each aspect of their identity was independent of others. On a community level, Axtell's (1999) participants talked about building inclusive communities where they could be their 'whole self'. Tamsin Wilton (1997) and Benjamin Lipton (2004) also point to the dearth of research addressing LGB people's experiences of chronic illness and draw largely on personal and professional experience to identify some of the issues for lesbians and gay men (respectively) living with chronic illness. Wilton (1997) indicates that lesbians living with chronic illness may experience isolation from other lesbians and lesbian communities; however, she suggests that those who do maintain contact with lesbian communities may find them a source of support. She proposed that lesbian communities may be better able to recognize, understand and challenge stigma associated with chronic illness given their experience of stigmatized sexual identities.

Lipton (2004), drawing on his professional clinical experience and his own research about colon and rectal disease in gay men (Lipton, 1998) asserts that HIV has become a 'litmus test of health' within gay male communities and that other illnesses may be trivialized. According to Lipton, gay men with chronic illnesses other than HIV are placed to the margins of both a heteronormative mainstream healthcare system and a HIV-centric gay community. Hanjorgiris et al. (2004) also suggest that an idealization of the body and the high value placed on sex within gay male cultures may result in changes to physical appearance and

sexual problems being more distressing for gay men than heterosexual men. Furthermore, Genke (2004) suggests that ageism may be more pronounced within gay male communities, further exacerbating the difficulties older gay men living with chronic illness face.

Lipton (2004) suggests that gay male communities need to move beyond a 'HIV-centric' to a multi-issue approach that addresses the needs of gay men with non-HIV related chronic illnesses. Similarly Wilton (2000, 2002) notes that while research concerned with preventing the continuing spread of HIV is vitally important to the health of gay and bisexual men, its dominant focus has had the unintended consequence of making 'lesbian and gay health' synonymous with 'sexual health'. Wilton (2000, 2002) argues that this is problematic because it reinforces the social construction of lesbians and gay men as entirely sexual beings and has meant that the wider health needs of LGB people tend not to be recognized or researched.

With the exception of HIV/AIDS, sexual identity is often not thought to be relevant or connected to chronic illnesses. It has been suggested that this is a result of chronic illness being generally understood from a biomedical perspective, as prolonged physical conditions that affect individuals on a biological level (Fish, 2006; Wilton, 1997). Much LGBTQ health research (particularly in the USA) has been largely informed by biomedicine and conducted within a positivist-empiricist paradigm with a particular emphasis on epidemiology (Wolitski et al., 2008). As a consequence, not only have some health issues failed to be recognized, but as Epstein (2003: 158) points out 'the research agenda becomes defined around precisely those questions that are amenable to quantification and measurement' privileging quantitative over qualitative methods and making it harder for 'lay people' within LGBT communities to have their voices heard. Lesbian and gay 'critical health psychologists' have, alternatively, emphasized the need for qualitative approaches to LGBTQ health and called for LGBTQ health agendas to move beyond an almost exclusive focus on sexual health (Adams et al., 2004; Wilkinson, 2002).

Research exploring non-heterosexuals' experiences of chronic illness, such as the current study, falls well within the remit of critical health psychology with its aim of challenging mainstream psychology's reliance on liberal individualism and its failure to fully recognize the sociocultural, political and community dimensions of health (Murray, 2004). Unlike mainstream psychology, critical health psychology views health and illness as inseparable from relations of class, ethnicity, gender and sexuality (Hepworth, 2006; Murray, 2004). While there is a growing body of critical health research by LGBTQ psychologists (e.g. Adams et al., 2007; MacBride-Stewart, 2004, 2007), the experiences of LGB people living with chronic illness are largely unexplored. This is in contrast with feminist health psychology, which has begun to investigate the gendered dimensions of chronic illness (e.g. Peel et al., 2005; Seymour-Smith and Wetherell, 2006; Wilkinson, 2004).

In sum, there is insufficient understanding as to how sexual identity may be relevant to the experience of a range of chronic illnesses. The present study aimed to address this lack of empirical investigation using a (predominantly) qualitative online survey. The purpose

of the study was to elucidate some of the ways in which sexual identity may be considered relevant to LGB people's experience of living with a chronic illness by examining their perspectives.

METHOD

The Online Survey

The data presented here are drawn from an online survey that aimed to collect predominantly qualitative data regarding LGB people's views and experiences about their physical health and/or chronic illness(es). Following internal ethical approval, the survey was developed and SurveyMonkey.com was used to collect the data. An online survey was chosen because of the anonymity afforded to participants, to gain a diverse range of respondents and to capitalize on the international reach of the internet with the potential for a larger sample.

The survey was divided into three sections. Section 1 consisted of demographic questions about age, gender, sexuality, location, relationship status and occupation. Section 2 included questions about the respondents' general health and some quantitative questions about how they would describe their current health and weight, and if or how regularly they drank alcohol and smoked. These questions were designed to gain an insight into how they considered their own health rather than to gain objective measurements (e.g. calculating respondents' body mass indexes (BMIs)). The multiple choice questions in both of these sections were designed to be as inclusive as possible. Respondents could select 'other' and provide an answer in their own words. Section 3 differed depending on whether or not the respondent indicated that they had a chronic illness. Those who indicated that they did not have a chronic condition were asked further about their health behaviours and about their perceived risk of developing chronic illness(es) in the future. Those currently living with chronic illness(es) were asked about their experience of their illness. The majority of questions in this section were qualitative questions with space for respondents to write as much or a little as they wished (e.g. 'In what ways, if any, has your illness affected your personal life?'). The survey was designed to allow respondents to skip any questions they did not wish to answer in order to allow people to take part without having to report anything they did not feel comfortable disclosing².

The qualitative responses collected were typically brief, as online surveys are a limited method of collecting qualitative data because of the inability to ask participants to elaborate on their responses and the expectation that closed or quantitative questions will mostly be used (Riggle et al., 2005). To mitigate this expectation, it was explained at the outset that there would be qualitative questions and that respondents could write as much as they liked. The free text response boxes were also made larger than the standard SurveyMonkey boxes to indicate that long responses were welcome. The method does, however, provide a quick and effective way of collecting a large number of diverse views and experiences in participants' own words (see also Harding and Peel, 2007a).

Recruitment

Two methods of sampling were used: strategic opportunistic sampling and snowball sampling. The strategic opportunistic sampling consisted of (1) sending a recruitment email to 22 LGBT-related online mailing lists and (2) placing an online advert on a social networking site for five days. The online groups ranged from general LGBT-related groups (e.g. regional LGBT community electronic mailing lists) to groups with a clearer interest in the topic (e.g. LGBT health and disability groups). These were largely either based in the UK or had an international membership. For email lists of which we were not a member, a message was sent to the moderator asking if they would consider forwarding on the call for participants so that they could decide on the appropriateness of the message for their online group. Participants were told that the purpose of the study was to examine the attitudes and experiences of LGB people in relation to chronic illness. The online advert placed on a social networking site was designed to target males and females whose online profile indicated that they were 'interested in men' or 'interested in women' respectively. The snowballing method consisted of emailing 96 of our own personal contacts who were asked to circulate the email among their networks as well as including a link to the survey in our email signatures.

Respondents

The survey went live on 14 May 2008 and remained online for eight weeks, at the end of which the survey had received a total of 364 respondents. Of the total number of respondents, 190 (52.2%) indicated that they had a chronic condition (approximately 60% of which had more than one). It is these respondents that were living with chronic illness that will be our focus for the remainder of this article. Of those with a chronic illness 50 percent (n = 94) identified as female, 44.1 percent (n = 83) identified as male, 2.1 percent (n = 4) identified as trans male (female-to-male), 0.5 percent (n = 1) identified as trans female (male-to-female). Six respondents (3.2%) selected 'other' (examples include 'gender queer' and 'intersexed male'). The majority described their sexual identity as either lesbian (44.1%, n = 83) or gay (39.4%, n = 74) while 10.6 percent (n = 20) identified as bisexual and 5.9 percent (n = 11) selected 'other' (e.g. 'queer', 'polysexual', 'no label'). The majority of respondents were aged over 30 years (80.8%, n = 152), with 7.4 percent (n = 14) 18–24 years, 11.7 percent (n = 22) 25–30 years, 22.9 percent (n = 43) 31–40 years, 23.4 percent (n = 44) 41–50 years, 25.5 percent (n = 48) 51–60 years, 8.5 percent (n = 16) 61–70 and 0.5 percent (n = 1) over 70 years of age. From the men that indicated their relationship status, 42.2 percent (n = 35) were in a same-sex relationship with a further 8.4 percent (n = 7) in a legally recognized same-sex relationship. Three men (3.6%) were in a differentsex marriage and 37.3 percent (n = 31) indicated that they were single. Of the women that indicated their relationship status 36.7 percent (n = 33) were in a same-sex relationship with a further 16.7 percent (n = 15) in a legally recognized same-sex relationship. One woman (1.1%) was in a different-sex marriage and 42.2 percent (n = 38) were single. The majority of respondents were from the USA (57.5%, n = 107) and the UK (36.6%, n = 68) with other responses from Canada (n = 5),

Ireland (n = 2), Denmark (n = 1), Spain (n = 1), Australia (n = 1) and New Zealand (n = 1). The majority classified their ethnicity as 'White European'/'White other' (84.7% n = 160). The remainder who responded to this question selected 'Black Caribbean' (1.1% n = 2), 'Black other' (1.1% n = 2), 'Pakistani' (0.5% n = 1), 'Chinese' (0.5% n = 1) 'Asian other' (0.5% n = 1), and 10.6% (n = 20) selected 'other' – these included four respondents who described themselves as 'Native American', three as 'Hispanic', one as 'African American' and two as 'British/Anglo Indian'. Over half described their current occupation as 'professional' (51.9%, n = 97) while 8 percent (n = 15) indicated that they were retired and a further 10.2 percent (n = 19) specified that they were retired because of ill health or disability. It was specified that a chronic illness meant a 'long term condition'. Overall, 52 different illnesses were provided by respondents. The five most commonly reported physical chronic illnesses in the sample were arthritis (20%, n = 38), hypertension (20%, n = 38), diabetes (15.3%, n = 29), asthma (14.2%, n = 27), and chronic fatigue syndrome (7.9%, n = 15)³. Table 1 provides a list of the illnesses reported by the sample on more than one occasion.⁴

TABLE 1: Illnesses reported

Illness	n	%
Arthritis	38	20
Hypertension	38	20
Diabetes	29	15.3
Asthma (moderate/severe)	27	14.2
Mental illnesses	19	10
Chronic fatigue syndrome	15	7.9
Multiple sclerosis	14	7.4
Cancer	12	6.3
HIV/AIDS	12	6.3
Osteoporosis	10	5.3
Coronary heart disease	9	4.7
Fibromyalgia	8	4.2
Epilepsy	7	3.7
Hypothyroidism	7	3.7
Chronic pain	6	3.2
Irritable bowel syndrome	6	3.2
Liver disease	6	3.2
Cardiovascular disease	5	2.6
Polycystic ovary syndrome	5	2.6
Autoimmune diseases	4	2.1
Colitis	4	2.1

Severe allergies	3	1.6
Chron's disease	3	1.6
Degenerative disk disease	3	1.6
Endometriosis	3	1.6
Kidney disease	3	1.6
Skin conditions (e.g. psoriasis)	3	1.6
Sleep apnea	3	1.6
Genital herpes	2	1.1
Hepatitis C	2	1.1
Lupus	2	1.1

Note: The sum total of these percentages is greater than 100% because many respondents indicated that they had more than one chronic illness.

Method of Analysis

Thematic analysis was used to analyse the qualitative questionnaire responses (Braun and Clarke, 2006). The analysis takes a critical realist epistemological standpoint, treating respondents' written accounts as representative of their lived 'reality' while acknowledging that the meanings given to experiences are mediated by the sociocultural context (Willig, 1999). Of those respondents with chronic illness(es), 158 provided written comments for all or some of the qualitative questions, resulting in approximately 90 pages of data. Our analysis is based on these 158 respondents. The responses to the qualitative questions were read carefully and coded. The coded segments of data were then grouped together into provisional categories, with some responses included in more than one category. The coded data were then sorted into themes before recoding any additional data into the themes which were originally missed. The analysis does not attempt to describe the content of the entire data set but rather was coded around how respondents' sexuality and illness intersected. For example, while we reflect on experiences of heterosexism within healthcare services, many positive experiences were also recounted about general healthcare that did not (at face value) relate to the respondent's sexual identity and so were excluded from the analysis. For this reason, the analysis could be described as more 'theoretical' (or 'analyst driven') than 'inductive', as the coding process was driven by our analytical interest in how sexual identity and health interact for LGB people with chronic illness within our data set rather than to provide a description of the data overall.

While there are many issues that will be specific to individual diagnoses and specific to those who identify as either lesbian, gay or bisexual, we suggest that there are a number of common features of both living with various chronic illnesses (Dimond, 1983) and identifying as lesbian, gay or bisexual. The common features that we will highlight in the following

analysis are: (1) ableism within LGBT communities; (2) isolation from LGBT communities and other LGB people living with chronic illness; (3) heteronormativity within sources of information and support; and (4) homophobia from healthcare professionals. In the following analysis respondents are referred to by their respondent number, sexual identity, country of residence and the illnesses the respondent specified that they were living with. We have edited the data to remove typos and grammatical errors.

ANALYSIS AND DISCUSSION

LGBT Communities: Ableist or More Accepting of Differences?

A number of respondents expressed the view that the only illnesses that lesbian and gay communities have responded to are HIV/AIDS (or other sexually transmitted infections) among gay and bisexual men and breast cancer among lesbian and bisexual women:

In these [LGBT] communities if you don't have AIDS or Breast Cancer you don't get no respect. They are not aware or inclusive of others with disabilities in my experience! ... they need to realize that neuroimmune disease is eating up our lesbian communities and provide the same kind of support and activism that AIDS and Breast Cancer have gotten. ME, MS, Lupus, Lyme, Arthritis, and other progressive inflammatory conditions are so very common and so ignored. (R249, white lesbian, Canada, arthritis, CFS)

Some felt that LGB people, like themselves, with illnesses other than HIV/AIDS or breast cancer were ignored within their communities and in the above statement, the respondent appears to try to frame her own illnesses as 'lesbian health issues', emphasizing a sense that in order to gain community support, a health issue must be seen as unique in some way to that community. As Epstein (2003) indicates, however, as long as LGBT communities view themselves as having distinct 'health issues' they will fail to attend to illnesses that affect a substantially large number of people within those communities but that are not necessarily restricted to or more common within those communities.

Respondents' accounts about how supportive LGBT communities are of those with chronic illnesses were mixed. Some felt that LGBT communities mirror the ableism of society in general, for example:

LGBTI communities are wilfully ignorant about chronic illness – they mirror society's attitudes that we are malingerers, whiners, people who don't take care of ourselves, or otherwise people of no value whatsoever. To become disabled by chronic illness is to cease to exist. I have been abandoned by virtually all of my LGBTI friends (including former partners) and communities. (R269, white lesbian, USA, arthritis,

diabetes, hypertension, liver disease, idiopathic anaphylaxis, sleep apnea, hypothyroid, autoimmune disease, idiopathic angioedema, eczema)

Others commented that LGBT (although mainly gay male) communities particularly stigmatized those with chronic illness because of a culture that emphasizes bodily perfection, idealizing 'slim', 'fit' and abled bodies. For example, one respondent commented about how stereotypes of gay men had presented him with difficulties:

Having to battle the cultural stereotypes that queers (especially gay men) are supposed to be the fit, buff model of health, and that "these things don't happen to us" has been a difficult mental barrier. (R101, black gay man, USA, diabetes, sleep apnea)

A number reported feeling the need to be 'perfect' to be accepted within LGBT communities:

the LGBT community, feels that if you are not "perfect" then you are not worthy of their taking the time to get to know you. (R201, white gay man, USA, type 1 diabetes, kidney disease)

While many of these comments focused on gay men and gay male communities in particular, lesbian communities were also described as ableist:

If you aren't able bodied, slim, athletic, and go go go, lesbians just don't know what to do with you. (R268, white lesbian, USA, asthma, CFS, degenerative disk disease)

In contrast to this were accounts of LGBT communities being more supportive and understanding of chronic illness than society in general. In particular, some felt LGBT communities are more accepting and inclusive of people's differences, including differences relating to health and (dis)ability. For example:

Probably the most support that I get from the LGBT community is a sense of belonging. I identify as being a member of the LGBT community more than I identify with being a member of my chronic illness community. One thing I have found, however, is that within the LGBT community there tends to be a more compassionate understanding of individuals who are 'different' than I tend to find in mainstream society. (R387, white bisexual man, USA, arthritis, arnold chiari malformation, degenerative disk disorder)

Some respondents reported feeling that certain sections of LGBT communities are more accepting and inclusive than others. For example one participant felt that bisexual communities in particular are more supportive:

I think being bisexual – and identifying as such ... has put me in contact with people and attitudes that are more inclusive and supportive of differences. Bisexuals are not necessarily more knowledgeable about illnesses or disabilities but it has been my experience that when told about them they're more likely to accept and advocate ... The LGBT community is very mixed in their attitudes ... It's also broken up by gender and orientation – most gay men (with a few exceptions) seem to be very fatphobic and very nerdphobic, and to basically not give a shit about anyone but themselves. Lesbians and transmen are either very politicized and attempting to be inclusive, or apathetic and hating everyone who is different from them. Bisexual women are the most likely to be accepting of difference, although there are of course quite a few who aren't. Most of my friends are bisexual women ... And my one asexual friend (who has chronic illnesses herself and is a disability activist) has been tremendously supportive in all kinds of ways. (R213, white bisexual woman, USA, hashimoto's thyroiditis)

There was a sense among some respondents that LGBT communities in general are more accepting of 'difference', perhaps as a result of being treated as 'different' because of their sexuality. Here this respondent appears to suggest that she finds members of LGBT communities who are 'politicized' to be more inclusive and accepting of those living with chronic illness.

Isolation from LGBT Communities and the Desire to Affiliate with Other Chronically Ill LGB People

Respondents commented on the many different ways their illness had impacted on their social life including relationships ending as a result of their illness, difficulties in dating and finding new relationships or sexual partners. A number of respondents with debilitating illnesses also reported, as Wilton (1997) suggested, a sense of social isolation from other LGB people and LGBT communities:

My former LGBTI communities and friends have completely abandoned me. Once you are forced to go back home to live with Mommy, you no longer exist, apparently ... The physical and social isolation are the worst aspects of being chronically ill ... An LGBTI person who has to live with his/her heterosexual family is more socially isolated than a heterosexual person in the same situation. I am completely cut off from any local community. (R269, white lesbian, USA, arthritis,

diabetes, hypertension, liver disease, idiopathic anaphylaxis, sleep apnea, hypothyroid, autoimmune disease, idiopathic angioedema, eczema)

Such respondents felt 'abandoned' and 'cut off' from the communities to which they once felt they belonged as their health deteriorated. This respondent refers to living with her 'heterosexual family' as being more isolating for her, than it would be if she were heterosexual. Another respondent commented on the difficulties of finding someone ('gay/straight') to assist them in maintaining contact with LGBT communities:

I have no social life at all, cannot go to the city without assistance cannot get to the gay area of the city ... and am totally unable to get any volunteer gay/straight to assist me to the queer quarter even to pick up a pink paper ... be gay and disabled and you find out who your friends aren't, I have NO support at all you become so very isolated, in all ways. (R273, white lesbian, UK, MS)

Inaccessibility was raised by a number of wheelchair users who reported that:

many gay and lesbian venues are not wheelchair accessible. (R123, black lesbian USA, hypertension, MS)

Others with illnesses such as diabetes, asthma and epilepsy reported avoiding LGB venues such as bars and nightclubs for health reasons. As well as expressing a sense of isolation from LGB people generally, some reported that their illness made them feel like a minority within a minority and felt isolated from other LGB people with their illness (see also Bennett and Coyle, 2007 who reported similar findings among gay men with learning disabilities). For example, one respondent commented:

I feel like the only person with this condition amid the LGB community. (R156, white lesbian, UK, Crohn's disease).

A number of respondents expressed a desire to affiliate with others who shared both these aspects of their identity:

I have felt extremely isolated because it is very difficult to find gay people with my illness. (R222, white lesbian, USA, autoimmune disease).

Here, not knowing others who both have a chronic illness and identify as LGB was described as adding to feelings of difference and isolation. Those who had other LGBT friends with a chronic illness reported this as being particularly helpful. For example, one gay male respondent commented:

I receive invaluable support from LGBT friends who are diabetic and LGBT friends who are partnered with diabetics. (R255, white gay man, USA, diabetes)

A bisexual woman wrote:

I know many lesbians and transgendered men with PCOS, and we have provided support to each other. (R204, Hispanic bisexual woman, USA, PCOS)

Another respondent wrote about how he and his partner's shared experiences of living with chronic illness formed a positive part of their relationship together:

My new partner is understanding about the ED [erectile dysfunction]. In fact, he has a chronic illness himself, being a Type I diabetic since the age of 9 ... I think the fact that we both have to deal with our bodies not being the way they were when they were more completely healthy is part of our bond. (R153, white gay man, USA, prostate cancer)

A number of respondents reported having used the internet to find other LGB people with their condition (or simply other LGB people with a chronic illness) and reported these networks as good sources of support:

I am part of an online support group, of other lesbians with similar problems and they are a wonderful emotional support system for me. (R268, white lesbian, USA, asthma, CFS, degenerative disk disease)

I belong to a diagnosis specific LGBT on-line support group that has been wonderful. (R173, white bisexual man, USA, arthritis, hypertension, prostate cancer)

For some, however, these groups were not as active as they would have liked:

Through the internet I have contacted a number of LGBT people with ME. We have formed our own support group online. Personally I have received a good deal of emotional support from the group and have tried to give such support in return. The group has been very inactive recently though. (R198, white gay man, UK, asthma, CFS, type 2 diabetes)

Some of these online groups were created by the respondents themselves, utilizing the internet to form contact with others like them. Such statements parallel comments made by Lipton (2004) who points to the general lack of opportunity to integrate one's (non-hetero)sexual identity with one's identity as someone living with a chronic illness and also

echoes one of Axtell's (1999) participants who desired a community where she could be her 'whole self' but felt that she would have to create such a community herself. While some respondents reported that they felt no need for LGB specific support and that local support groups provided for their needs, others felt that such groups did not cater for them as LGB people as the next theme will make clear.

Heteronormative Support

Few respondents (with exception to some in the USA) had access to face-to-face groups for other LGB people with their illness. While some did not feel the need for such groups, others represented general illness-related support groups as groups of predominantly heterosexual people and potentially homophobic environments. Some reported that they felt unable to disclose their sexual identity for fear of homophobia. One respondent stated that this was because of the age of many people with her illness:

I find many people with my condition are older and have therefore not felt very comfortable in being out to them. (R53, white lesbian, UK, colitis, hypothyroidism)

Another stated that the perceived need to conceal her sexual identity meant that, for her, such groups were:

just another oppressive atmosphere that adds to my stress, and doesn't help enough to counteract it. So unless they are lesbian/gay focused, they are not helpful to me. (R268, white lesbian, USA, asthma, CFS, degenerative disk disease)

For others, perception of support varied depending on the particular group. For instance, one respondent reported that she had felt comfortable in a previous local support group, but feels uncomfortable in the group she currently attends:

I am also part of a support group at my hospital. I was part of another group there that recently folded. I was comfortable in the old group and was free to come out even though I was the only queer person in the group. I'm not comfortable at all in this new group. (R163, white lesbian, USA, arthritis, cardiovascular disease, coronary heart disease, diabetes, hypertension, liver disease, congenital generalized lipodystrophy).

For those who perceive support groups as presumed heterosexual and potentially hostile environments, the intended aim to foster feelings of being understood and relating to each others' experiences are unlikely to be achieved. Some reported that the predominantly heterosexual membership of support groups did not share the same concerns as themselves, which made such groups unappealing and limited their ability to address their needs:

PCOS communities are full of straight women who discovered they have PCOS when they were trying to get pregnant. Totally unappealing to me. (R204, Hispanic bisexual woman, USA, PCOS)

Other distinctions that respondents made included female partners' supervision of men's health within heterosexual relationships and female partners being more vocal than men within 'straight' or 'mixed' support groups:

The culture difference between gay and straight makes it hard for us to mix with them in support groups. For instance many Straight men with diabetes don't cook for themselves so they aren't really involved in their own dietary needs and view their 'wife-mommy' as the one who feeds them and selects their diet. Gays and lesbians don't live in these kind of gender role play acting ways. (R157 white gay man, USA, arthritis, asthma, diabetes, hypertension, chronic pain)

Interestingly, in the network in which my [gay specific] support group met, we found that when any of us went to the straight or mixed support groups, the straight men generally seemed much more reticent to speak in the groups. Their wives were generally the vocal ones, asking questions and sharing. In the gay group, we, the patients, were much more active for ourselves. (R153, white gay man, USA, prostate cancer)

A number of respondents also described other forms of support, such as written information in books, magazines and illness-related charity websites as heteronormative in their assumption that the reader is heterosexual. This was most commonly reported about sources of information addressing sexual problems related to illnesses, for example:

Most of the books I read were not very inclusive. Sexuality was presumed to be hetero, and, of course, many special issues were thus not even contemplated (e.g. the additional degree of hardness one needs to penetrate an anus, as opposed to a vagina, the nonprocreative meanings of semen, etc.). (R371, white gay man, USA, prostate cancer)

Others, however, also commented that they felt that LGB people were invisible within written resources. For example, one respondent with asthma stated:

I read Asthma UK magazine and to be honest I have never seen info specific to LGBT people. It seems sadly that only diseases/medical conditions associated with gays etc such as STDs/AIDS are inclusive or target sexual identity. This is very negative and not supportive for those of us LGBT with chronic conditions. (R127, white gay man, UK, asthma)

As Lipton (2004) suggested, respondents described feelings of not only being invisible within or ignored by LGBT communities, but also by sources of information and support regarding their illness, highlighting the need for LGB specific support. One respondent highlighted that 'minorities' are only catered for by mainstream support organizations and charities if those minorities have a higher incidence of the illness while others are ignored. He specifically pointed out that while diabetes charities target support at ethnic minorities and cater for them specifically there is no such support available for LGB people with the illness:

A large diabetes support community does exist, but they do so to the exclusion of other types of identity (such as sexual identity) UNLESS there is a higher incidence of diabetes, as within ethnic groups. (R245, white bisexual man, US, type 1 diabetes, hypertension).

Heterosexism/Homophobia from Healthcare Professionals

As well as reporting heteronormativity from sources of support, a number of respondents recounted experiences of homophobia from healthcare professionals. One such respondent stated that:

homophobia is still an ever present reality (R80, white Queer, UK, arthritis, hypertension, dermatitis, diverticulosis)

These experiences mainly took the form of healthcare professionals informing the respondents of their anti-LGB views. For example, one respondent described negative experiences with a number of nurses, stating that they had:

felt entitled to pronounce judgementally about my lifestyle at a point when I am feeling physically unwell and, therefore, vulnerable. (R386, white gay man, UK, arthritis, colitis, kidney disease)

Such experiences took place in a number of contexts, including doctors' surgeries, hospitals and for one respondent, in their own home:

Homophobic doctors are a nightmare! I always disclose my sexual identity to my medical community and healthcare professionals who have not dealt with their homophobia make me very uncomfortable. I also had an agency appointed homecare worker for almost six months and it was a terrible and very disempowering experience. This homecare worker constantly made disparaging remarks in my home and it was difficult for me to finally make a complaint against her. I was afraid I might

lose my homecare benefits or get someone else who was worse. (R279, white lesbian, Canada, arthritis)

Such statements concur with the findings of other studies that suggest that despite wider changes in attitudes to LGB people, homophobia in healthcare provision is still a reality (Beehler 2001; Eliason and Schope, 2001). The previous comment also draws attention to the fact that while most research has focused on LGB people's experiences of healthcare professionals within healthcare settings such as doctors' surgeries and hospitals, those with chronic illnesses who require home care may also experience homophobia in their own home.

Another issue raised by a lesbian with 11 different illnesses (R269, white lesbian USA) was that unlike LGB people generally, those living with a number of chronic illnesses have contact with a greater number of healthcare professionals, which she described as 'upping the odds' of coming into contact with professionals with anti-LGB views. While such instances of homophobia may be rare, such stories among LGBT communities may result in a more widespread fear of homophobia from medical professionals. Indeed a small number of respondents reported not disclosing their sexual identity to healthcare professionals for fear of a homophobic response and its possible implications for the care they receive, for example:

I have not discussed my sexual identity with any healthcare official associated with my diabetes care. This is because I fear their reaction and how it might affect my care. (R255, white gay man, USA, diabetes)

Of those who had chosen to actively disclose⁵ their sexual identity to healthcare professionals, some reported doing so specifically to 'test' that a healthcare professional would be comfortable with this and to evaluate their safety:

It's very important that I'm sure they will be ok with my orientation ... The only way to test them is to come out right away and watch them. Otherwise you're not safe. (R157, white gay man, USA, arthritis, asthma, diabetes, hypertension, chronic pain)

There were, however, also comments about respondents' positive experiences with healthcare professionals who knew their sexual identity, for example:

Most of my gynecologists [related to her PCOS treatment] have been very supportive and have been helpful when I tell them I'm queer. (R204, Hispanic bisexual woman, USA, PCOS)

A number specifically made a connection between their positive experiences and their geographical location:

I've had a lot of positive experiences with healthcare professionals. We live in a queer area, I've had surgeries here and my partner has always been welcomed and treated as my partner and we did not need to 'prove' our relationship status. (R160, white Queer, USA, hypertension, endometriosis)

One respondent also referred to gender, ethnicity and affluence as reasons for his positive experiences of healthcare:

All of my experiences with healthcare professionals have been positive. I am an affluent white male, and so am privileged to be able to afford adequate health insurance, and can choose my doctors. (R364, white gay man, USA, hepatitis C)

So while positive experiences were not uncommon among the sample, many of such respondents positioned themselves as 'privileged'. Another reason provided for positive experiences were as a result of having sought or happening to have healthcare professionals who themselves identify as lesbian, gay or bisexual:

I was able to find a gay male GP in the last few years and that was an incredibly positive experience. (R279, white lesbian, Canada, arthritis)

I have been treated by a man who is a gay physician and he is sensitive to the issues that are faced by LGBT individuals. However, many of my other physicians are not and often discussing general health issues becomes uncomfortable. (R387, white bisexual man, USA, arthritis, arnold chiari malformation, degenerative disk disorder)

A few also described belonging to 'LGBT health practices' or finding doctors that advertised themselves as 'queer friendly'. Whilst no specific question asked directly about heterosexism/homophobia⁶ this was (perhaps unsurprisingly) a common theme.

CONCLUSIONS

In this analysis we have highlighted some of the ways that sexual identity may be relevant to the experience of living with chronic illness. Despite the respondents living with a myriad of different illnesses, being of different genders, identifying their sexual identity in various ways and living in different countries, their experiences have much in common. What unites them is not 'epidemiological similarity', but common experiences of oppression, invisibility and isolation from others like themselves (Epstein, 2003).

Respondents expressed differing perspectives as to how supportive LGBT communities are of people living with chronic illness. Respondents highlighted the way in which LGBT movements frame health and illness and felt that those whose illnesses are not currently framed as 'gay/lesbian health issues' feel invisible within and ignored by those

communities. As Fish (2006) notes, concepts of relevance based on a biomedical model that reinforces the idea that LGB identities are only related to sexual health issues need to be problematized by LGBT researchers and activists. To achieve this goal, LGBTQ psychologists could usefully draw on critical health psychology and qualitative methods to explore non-heterosexual's lived experiences of chronic illness. Epstein (2003: 156) suggests that it is unlikely that 'academic health researchers will be prone to value the kinds of experiential, community-based knowledge about health, illness and sexuality that are cultivated in grassroots activists circles'. By drawing on the social activist approach of critical health psychologists who define themselves as 'scholar-activists' (Murray and Poland, 2006), LGBTQ psychologists could work with grassroots activists and LGBTQ communities to value precisely these kinds of knowledge.

Respondents in this study described feeling isolated from other LGB people with their condition and uncomfortable within support groups with a primarily heterosexual membership. Many expressed a desire to affiliate with others like themselves and, paralleling Axtell's (1999) study, some respondents had attempted to create networks where they could be their whole selves by utilizing the internet. Perhaps one practical way that both LGBT communities and health organizations can be of assistance is to help such groups be more active by coordinating and/or advertising such supportive networks. This analysis also highlighted that some LGBT people feel that their concerns are not represented in published information about their illness and continue to experience or fear homophobia within healthcare services. These findings emphasize the need for LGB-specific support. We would argue that structural prohibition of discrimination alone is unlikely to eradicate heterosexism and heteronormativity within health services, and it should not be assumed that mainstream services will adequately cater for the needs of LGB people (see Harding and Peel, 2007b for a discussion of the limits of anti-discrimination law). In the area of health, LGBT activists have focused on gaining recognition of same-sex partners by health providers and the prohibition of discrimination within health services, and such efforts appear to have been successful. For example the UK government has introduced the Equality Act (2006), which outlaws discrimination (including on the basis of sexual orientation and gender identity) in the provision of goods and services, while in the USA, Barack Obama has specifically spoken of hospital visitation rights for same-sex couples and of freedom from discrimination for lesbians and gay men (Obama, 2008). We would argue, however, that top-down structural change should not be seen as eradicating the need for grassroots health initiatives from within LGBT communities.

Some limitations of the methodology should, however, be noted. While the respondents were diverse in terms of age, geographical location and the illnesses they live with, they all had a number of features in common; for example, all were literate and had access to the internet. The respondents could all be described as multiply marginalized as all were non-heterosexual and living with a chronic health condition. However, respondents differed in relation to other dimensions of marginalization/privilege such as age, gender, race (with the majority being white) and social class. This online survey looked specifically at the

intersection of sexuality and chronic illness and differences and variations based on other aspects of identity such as age and race were difficult to tease apart. In-depth interviews are perhaps a better method when looking at several dimensions of intersectionality. We are not in any way trying to suggest that people with 'chronic illness' are a homogenous group and some points raised in our analysis may be specific to the particular illnesses they live with. We do, however, believe there are a number of benefits to this kind of methodology as a basis for further research. While our data is based on a convenience sample, the illnesses most prevalent in the sample mirror those most prevalent in the general population. However illnesses such as arthritis, heart disease and diabetes have yet to be researched in non-heterosexual contexts. Researchers and healthcare professionals should not assume that everyone with a particular illness will have similar lives or that their knowledge about how people experience illness will necessarily hold true for LGB people. We have argued that by employing a framework of critical health psychology, we may begin to explore the lived experiences of health and illness for LGB people and better understand the need for LGB-specific support for a range of illnesses experienced within LGBT communities.

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NOTES

1. We refer to our respondents as LGB people as opposed to LGBTQ people as the focus here was on sexual rather than gender identity and the majority identified as either lesbian, gay or bisexual (approximately 94%). We sometimes use the phrase 'non-heterosexuals' for inclusivity, despite having reservations about the term because LGBTQ identities are signalled negatively against heterosexuality via 'non'. The phrase 'lesbian and gay health' is used to indicate the marginalization of BTQ people within the health literature. We use the more common acronym 'LGBT' when referring to the social and political communities/groups to which LGB people may belong, and within the data extracts some respondents also added 'I' (for 'intersex') when referring to these communities.
2. This is excluding the initial questions regarding consent and a question about whether or not the respondent had a chronic illness that was required to direct the respondent to the next appropriate question.
3. By 'physical' here we mean those not generally deemed as 'mental' illnesses, as this was the focus of study; however, we acknowledge debates about the physical origins of mental illnesses.
4. A further 21 illnesses were reported on just one occasion. These were: angioedema, arnold chiari malformation, antiphospholid/Hughes syndrome ('sticky blood syndrome'), Barretts syndrome, Benign enlargement of the prostate, chemical sensitivity, congenital

generalized lipodystrophy, diverticulosis, electrical sensitivity, gastro-oesophageal reflux disease, Hepatitis B, Hirschprung's disease, hypotension, myoclonic dystonia, polycythemia, pulmonary embolism, rhinitis, sensory hypersensitivity, shingles, spinal stenosis, trigeminal neuralgia.

5. See Eliason, (1996) for a discussion of 'active' and 'passive' disclosure/non-disclosure.

6. Respondents were asked generally about any positive or negative experiences they had had with healthcare professionals and about whether their healthcare providers were aware of their sexual identity.

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